

“You have come to the right place”

The final article in a three-part series

Bhavishya sits opposite me; she looks like a 10-year-old, a thin 10-year-old, with wrists I could easily encircle with my thumb and forefinger; thighs the circumference of my upper arms. Dark circles underline her eyes, which are downcast under long lashes; a surgical mask covers her nose and mouth. Bhavishya looks 10, but I learn she is 17, being treated for extremely drug-resistant tuberculosis. Less than a year ago, she weighed about 62 pounds. She’s four-foot-nine.

We’re sitting in an examining room in the Médecins Sans Frontières (MSF) clinic in Mumbai, India. Behind me, a noisy fan blows air vigorously across the table and out the window. Bhavishya wears a surgical mask. Like everyone else in the small room, I’m wearing a N95 respirator. Sitting beside Bhavishya is her father, Vishwas, a 49-year-old cobbler who owns a roadside stall. He has agreed to tell her story to *CMAJ* through an MSF interpreter. It rapidly becomes an all too familiar story of systemic failure.

My daughter was diagnosed in 2012, when she was in 9th grade. Fourteen years old. ... There was a wedding in

the family. We learned later that two girls, distant relatives, had tuberculosis. No one knew. I suspect she got her infection from one of them. A year later it was confirmed; both had extremely drug-resistant tuberculosis. But we didn’t know that at the time. My daughter starting getting fever and we went to a private Ayurvedic doctor who gave us some medicine. After 15 days, still the fever didn’t go down. We went back to the doctor, who said keep trying a few days. She still had a high fever, so we went to a family doctor; she was tested and it was positive for tuberculosis.

He said we had a choice between public or private care. I saw banners from the government saying that TB could be cured. In the private system it was going to cost three to four lakhs [\$6314–\$8500]. I couldn’t afford that; I’m a cobbler. And if we have such a nice system in place, well, I decided to go public. On our first visit to the Mumbai Municipal Corporation Health Centre, I was told it was curable; don’t worry. The doctor didn’t touch my daughter. He filled out a form and we started the [basic TB] drug regime. On every visit, the doctor did the same thing: prescribing at a distance. They didn’t take her temperature or listen to her chest, even though

I asked them to. Five to six months later, her sputum test came back positive. She was not improving; the regime wasn’t working. I asked what level of tuberculosis she had and the doctor said their protocol was to do the basic treatment because we had her [initial] test done privately.

Vishwas pauses to explain how Bhavishya was kept away from other children during her illness, but how he tried to help her have a life that was normal and fun; they went to movies wearing masks. “I told her, ‘I am there with you forever’.” She leans her head against his shoulder. He continues.

I discussed her case with a social worker in my community; we were concerned because she wasn’t improving. The social worker said to get a culture, which cost 7000 rupees [\$147] in the Hinduja [private] hospital. That was too expensive. I asked the doctor in the public system why she hadn’t been tested and he said they were following their protocol. Other patients were waiting for culture and she was in the queue. Finally she got the culture and it was positive. ... He said they were caring for her. They said they have lots of burden and other patients. Then I said my daughter might die. I didn’t want to leave my daughter with them to die.

Bhavishya asks her father if it’s okay if she lies down on the examining table to rest. He asks us and we urge her to do so. She lies on her back, staring at the ceiling, one thin, jean-clad leg bent. She could be a teenager anywhere. Her father continues.

I went to my private doctor and voiced my complaints. My doctor sent us to a private chest hospital with specialists. The doctor studied her case, took sputum that first day and found she had been on the wrong regime for the last eight months. They put her on treatment for multidrug resistant [MDR] TB and said her treatment would take two years. By the time of her MDR diagnosis, she had been sick for eight or nine months. We sold our gold ... to raise money to continue the treatment. We were determined that she had to get rid of this disease. After



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Bhavishya was diagnosed with tuberculosis in 2012, but didn’t get the correct treatment until 2015.

20 months of treatment, she was still not better. We'd spent two-and-a-half lakhs on medicine and about two lakhs on diagnostics and consultations, a total of four lakhs [\$8500]. She struggled with the treatment. Her mother wondered if she was taking her pills. We made sure she did, then she'd go for a walk. Sometimes my daughter lost hope and said she wanted to die. We watched her closely. I had the feeling too: Why would I live if she died? I was on the verge of losing hope.

I consulted with the doctor because the sputum was still positive. ... She had another test and we learned it was extremely drug-resistant [XDR] TB. They added a few more drugs. That cost about another two lakhs [\$4250]. And on this treatment she started vomiting, losing her hair. She was dizzy, almost bed-ridden. She would get fevers in between that would last five hours or so. One of those fevers was so severe that she fainted. I called the doctor, but he wasn't there, so I took her to the first doctor in my neighbourhood. I carried her in my arms.

Tears well up; he rubs his eye under his chipped wire-framed glasses, swallows audibly, then continues talking.

That doctor gave her some basic medication for two days, but said she had to go back to the hospital where she was being treated. The hospital wanted to retest her — it would cost 50 000 rupees [\$1052] to get the test because she was too weak to produce the sputum herself. Plus the treatment would cost some lakhs again. I told them I had no more money. I'd sold everything. I'd borrowed money. All I had left to sell was the house. I asked for two days to think about what to do.

I went back and talked to my social worker friend, who told me about Médecins sans Frontières. I talked to a journalist friend and asked him to find out about MSF. I didn't want to take another chance. I'd tried public, I'd tried private. I wanted to try to find out if MSF was reliable. We came here with my journalist friend. The security person at the entrance said to us, 'You have come to the right place.' The doctor assessed her and we met with the patient support team and they



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Bhavishya has daily injections and takes 16 to 18 pills every day.

decided to take the case. We were told we would have to do all the tests and it would take 15 days. They got it done. [She was tested for 14 drugs; only 4 were working.] She was put on treatment for extremely drug-resistant TB six months ago. She weighed 28 kilos. Now she weighs 34.

Bhavishya climbs off the examining table and sits beside her father again. Vishwas pats her arm, a gesture of reassurance, seemingly for them both.

Coming to MSF felt good. Everyone from the moment you step in the door, from the security person on up, they all had said the same things: don't lose hope, eat well, take your pills on time. There's no stigma. Everyone supported us from the security person on up. The doctor explained the treatment; she spent real time with her. The mood here is so positive and the doctor is so passionate about her work. They are half the cure.

She has daily injections and takes 16 to 18 pills. And after eight months on treatment, she's still testing positive. In September, they changed her drugs, adding delamanid, which is available on compassionate-use basis. But after coming to MSF, things definitely got better. She feels hungry, she wants to eat. [MSF provides food rations.] There are no more fevers. These are positive things. That is something which is keeping us going.

Bhavishya tells us she doesn't feel like her health is improving, but that doesn't stop her from having dreams for the future. "When I see everyone helping me," she says, "I would like to pursue a career to help people who are excluded. I'd like to work with MSF or become a doctor." Soon, she will write her grade 12 exams; if she does well, she hopes to switch from commerce to science. During her illness, she has missed years of school, but continued to study on her own; she scored first class in her entry exams to high school.

"She was eligible to sit for the exam, even working at home," says Vishwas proudly. There is a pause in the conversation, and he delivers what seems to be a prepared speech, urging people with resources to help MSF. "They treat patients who can't get services anywhere else, whether public or private. They treat people regardless of their faith or class."

"While I'm waiting in reception for my daughter, I tell other people 'You are in the right place'." — Barbara Sibbald, CMAJ

Editor's note: The patient asked that her real name not be used; Bhavishya means future in Hindi. Vishwas (the father's real name) means trust/faith.

CMAJ 2016. DOI:10.1503/cmaj.109-5255